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The Perception of Alzheimer`s Disease in the Social Context of Turkey

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Abstract: Alzheimer's disease has moved to the front burners as a hot debate among the social scholars as well in the recent years. That is because although the causes of Alzheimer's disease are mainly seen as biological, the effects of it are usually displaying themselves socio-psychologically for both the aged and caregivers. That is why this study focuses on the reviews of debates on the conceptual framework of Alzheimer's disease to shed the light on its perception in Turkey. Since a person's condition declines with Alzheimer's, a fragile situation comes about in terms of social exclusion of him or her. It is not only his or her withdrawal from society, but also family members sometimes develop some exclusion practices against him or her due to heavy burden of disease on their shoulders. Therefore, this study examines the nature of social exclusion of the older adults facing Alzheimer's disease in case of Turkey. However, the social programs and services have been developed by the government for Alzheimer's patients to change the context of exclusion by promoting their social inclusion. In particular, social support system plays a strong role on the wellbeing of caregivers facing role strain. That is why this work aims at raising awareness in the society to see both faces of the same coin for benefit of patients and caregivers. Although Alzheimer's disease is not a new phenomenon, the understanding of this disease is still poor even in aging societies. In this respect, it is interesting to note that it is only evaluated in the field of psychiatry. Therefore, this article tries to develop a new understanding to see its reflections in a multidisciplinary perspective.

Keywords: Alzheimer's disease, Social exclusion, Aging, Perception, Dementia, Psychiatry

INTRODUCTION

Aging is a particular period of human life in which some physical, social, economic and even spiritual changes occur. In particular, physiological changes in biological structure of the human body with age bring about some chronic diseases. It is really hard for a person to accept these chronic conditions and adopt a new life revolving around these chronic diseases. Alzheimer`s disease is obviously one of the chronic conditions changing the course of a person`s whole life. Thanks to technological developments, health improvements, sustainable housing for the elderly, and special care units for people with Alzheimer`s, the developed world has made big progress in fighting harsh years with Alzheimer`s. However, coming to a developing world, one can easily see some problems even in diagnosing this disease, including its treatment and its physical, psychological, economic, and social impacts on the patient and his or her family. Before covering this big issue in the developing world, this paper will first introduce Alzheimer`s disease and its treatment options.

Defining Alzheimer`s Disease and Historical Background

There are plenty of definitions for Alzheimer`s Disease. According to Ramanathan[1], Alzheimer`s disease is a kind of dementia defined as a condition of chronic progressive deterioration of intellect, memory, and communicative action. Paul and Altstiel[2] define it as a progressive and dementing disease that generally occurs in late years. One can enlarge the list of these definitions, but most of the definitions include its chronic, memorial and late age aspects. For this reason, one can make a combined definition for this disease as follows: Alzheimer`s is a kind of chronic disease related to memory and old age with variable age of onset.

Alzheimer`s disease has a long history. According to Maurrer, Volk and Gerbaldo[3], in his paper published in 1907, Alois Alzheimer focused on the chronic health condition of a 51 year-old woman named Auguste D. It was just 4 years later when Emil Kraepelin related this condition to Alzheimer`s grand breaking work by naming it Alzheimer`s disease.

Alzheimer`s Disease in the Classical Texts and Its New Phases

In his paper, Alois Alzheimer [4] mentions a rapidly progressive impairment of memory. This refers scientist to look at arteriosclerotic changes, senile plaques, and neurofibrillary tangles in the brain of person suffering from this disease. In his example, he gives many symptoms and behavioral changes in individuals facing this disease. For example, he says:

> "She could no longer find her way around apartment...At times she believed someone wanted to kill her and began to scream loudly...Sometimes she is completely delirious, carrying around her bedclothes, calling for her husband and her daughter, and seeming to have hallucinations. Often she screams with a horrible cry for many hours." [4].

Also, he focuses on memory disturbances. He mentions that if someone shows an object to the patient, she knows but immediately forgets everything. While reading, she skips lines. Without a doubt, this preliminary work is still crucial in understanding "the disease of century" and "the birth of Alzheimer's Empires."

Clinical Alzheimer's disease can be divided into three distinct phases. According to Ramanathan[1], they are the forgetfulness phase, the confusional phase, and the dementia phase. The first phase is described by subtle decrement in memory functioning. For example, the patient misplaces the objects and has difficulty in remembering names. Also, social withdrawal, language disturbances, and mild comprehension are seen in the first phase. In the second phase, cognitive deterioration becomes more obvious. Memory loss, temporal and spatial disorientation, and poor judgment are major markers of this phase. In the final phase, there are profound disturbances in orientation, severe intellectual decline and even inability to recognize the close relatives. Also, there is a collapse in body system. For example, the patient cannot move and control his urine. Unfortunately, the result is death.

Evolution or Evaluations of Alzheimer's Disease

Chronologically, Alzheimer's disease has evolved or evaluated in three stages. According to Ballenger [5], they are classical time period, modern period and a sort of postmodern period. In the classical period, disease was brought into scientific focus by Alzheimer and Kraepelin. Modern period is characterized by technological and conceptual breakthroughs in developments in Alzheimer's disease. Postmodern period is marked by understanding Alzheimer's disease via molecular biology as well as by going beyond the scope of molecular biology. However it is hard to argue that such a linear evolution occurred in the developing world. Therefore, Turkey can be a good example in understanding the perception of Alzheimer's disease.

As Whitehouse [6] argues that older adults have suffered from progressive cognitive ability throughout history, but the perception about this loss has always differed from culture to culture and from society to society. Becker and Giacobini[7] argue that cultural variables such as traditions, customs and languages have a great relevance to diagnosis of Alzheimer's disease. They add that there is even not an exact standardized clinical criteria to diagnosis Alzheimer's disease in the developed world. One could easily understand how it is hard to build a consensus on diagnosis and treatment of this disease. However, our idea about the perception of the developing world about Alzheimer's disease in the case of Turkey is slightly different from this universal cultural variety.

The Perception of Alzheimer's Disease in Turkey

One difference is that what Whitehouse [6] mentions about the perception of Westerners before 1800s is still the case in Turkey. According to Whitehouse [6], before the late 1800s, dementia was thought to be caused by religious factors or degeneration in moral values. For this reason, it was associated to deterioration in personality instead of brain cells. He adds that humanity had to wait for the development of science and technology to associate disease with senile plaques and neurofibrillary tangles. It is over two centuries. The same story is still being told in some parts of the world. In some regions of Turkey, for example, people still associate Alzheimer's kind of disease to degeneration in moral values. It is a classical point of view that if somebody has harsh years in his or late years, the first evaluation of people is going back to sin of this individual in his or her young years. They says, "You see he or she is in his punishment days due to his or her bad deeds. That is why he or she is suffering from this disease." There is only one way to get rid of this disease. It is nothing than visiting a magician for "healing."

Although such an attitude toward Alzheimer's disease is not so prevalent as before, people are still looking for spiritual "causes" of Alzheimer's disease in Turkey. One can easily relate the involvement of psychiatry as continuation of this trend. Ballenger [5] mentions that even American psychiatry regarded Alzheimer's disease as the aged insane which was believed not to be cured. That is why the patients were kept in mental hospital throughout the first half of the twentieth century. This tradition has gained power in Turkey after a suspicion brought about by science to moral perceptions of disease. In spite of the development of nursing home phenomenon in the modern era, psychiatry has occupied the field of gerontology and aging related disease. In fact, mental hospitals are still the first station for persons developing Alzheimer's disease. As it is well known, this creates big problems in valid diagnosis and care for the elderly. Some nursing homes which are run by civic organizations and metropolitan municipality in Istanbul initiated some small scale Alzheimer's units, but they are still not enough to change the dominant tradition of psychiatry evaluating disease as insanity. Since psychiatry built a big "medical industrial complex" in the small island of "Alzheimer's empire," Turkey needs more time to hand in this clinical case to its real diagnosticians known as geriatricians.

It is interesting to note that coming to other illnesses such as diabetes, cancer and ulcer people prefer to see related physicians first, but according to Yasan and Gurgen[8], this is not the case for the diseases related to psychiatry and even people who have developed this disease are more prone to apply traditional methods. Since Alzheimer's disease is still seen as a condition only related to psychiatry, the traditional help-seeking behaviors are still dominant for Alzheimer's patients and their families.

As seen, in the developing world, biology hasn't been dominant in conceptualization of Alzheimer's disease as opposed to the developed world. In particular, psychological factors were employed more to picture this disease. Therefore, it has become hard to see this chronic condition in a way in which there is an interaction among biological, clinical and social-psychological factors.

Wither Hopes in Cure of Alzheimer's Disease

Up until now, humankind hasn't found a cure for Alzheimer's disease although some drug and non-drug treatments can help cognitive and behavioral symptoms of it. However, there are many ways to improve the quality of life for people with Alzheimer's. Without a doubt, prevention plays a key role before developing Alzheimer's disease for a person. In particular, age 65 and over are critical periods for a person to develop this disease even though there can be some onsets of disease before this age. According to Whitehouse and George [9], the rate of Alzheimer's case climbs in centenarians and supercentenarians. For this reason, good diet, mind protection, exercise, being away of environmental exposures and stress are gaining more importance for these people in preventing this chronic disease.

Alzheimer's: A Disease of Social Exclusion

It is narrated by our ancestors that old empires completely excluded people with leprosy. Although people with Alzheimer's don't face such a complete exclusion in modern empires, it is hard to say Alzheimer's disease is quite welcomed by our states and economic sectors. Since there is no hope for cure for Alzheimer's disease and the people with this disease are waiting death in hospice, assisted suicide has become one of the ethical issue in aging studies. In particular, Dr. Kevorkian's cases have raised a big question in minds whether or not such an assisted suicide can be done for keeping human dignity. Also, it has become quite vague whether or not family members play a role in assisted suicide to get rid of heavy economic and psychological burden of Alzheimer patients.

Post [10] has a quite interesting example for workplace discrimination done for potential Alzheimer's developing persons. In his idea, discrimination would easily be done against persons who can have a risk of developing Alzheimer's disease. This is quite alarming for citizens who have to live in a world exploded by Alzheimer's cases.

Post [10] adds that people with Alzheimer's disease face societal discrimination as well. That is because the core values of modern technological society are rationality and memory. As Bauman [11] states, rationality is a strong base of modernity, which is going back to Enlightenment. In particular, rationality and "strong memory" tests are taken as criteria in mapping the personal competence. Since people with Alzheimer's disease have started to lose both of them, they face exclusion from sphere of human dignity and respect.

Concluding Remarks

From the points mentioned above, one can safely draw the conclusion that Alzheimer's disease is a condition dragging individuals into acts of not remembering all past. This is really hard for an individual and his or her family to deal with a new life with language breakdown and not being recognized by a close life partner. Bedridden state and incontinence of urine and feces don't require more elaboration. Although there are many myths and stigmas associated with this condition, its effects show their real face on an Alzheimer's patient and his or her family as real as death. That is why Alzheimer's disease and death meet at the end.

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